

Note: It is recommended that this Data Set have two additional key variables:

- SITE (to distinguish the location where the data are recorded) and
- SUBJECT (to distinguish the patient/study participant)

**INTERNATIONAL SPINAL CORD INJURY PULMONARY BASIC DATA SET  
FORM (Version 1.0)**

Date performed: YYYY/MM/DD **PULMDT**

**Table #2**

**Pulmonary conditions present before spinal cord lesion (collected once):** **Table #1**

- None
- Asthma **ASTHMAHX**
- Chronic obstructive pulmonary disease (includes emphysema and chronic bronchitis) **COPDHX**
- Sleep apnea **SLPAPNHX**
- Other, specify **OTHPULHX** **OPULHXSP** \_\_\_\_\_
- Unknown

**Smoking history:** **Table #2**

- Never smoked  Former smoker  Current smoker  Unknown **SMOKNGHX**
- If a former smoker, which year did you quit smoking? \_\_\_\_\_ **SMKQITYR** **SMKNOYRS**
- If a former or current smoker, for how many years did (have) you smoked? \_\_\_\_\_ years
- If a former or current smoker, on average how many (cigarettes/cigars/pipes) do (did) you smoke on a daily basis (answer all that apply):
- \_\_\_\_\_ cigarettes **NOCIGRTS**
- NOCIGARS** \_\_\_\_\_ cigars
- \_\_\_\_\_ pipe bowls **NOPIPES**
- unknown

For former or current cigarette smokers only, the number of pack-years of smoking [(average number smoked daily)/20] x (number of years smoked): \_\_\_\_\_ pack-years

**SMKPCKYR**

**Pulmonary complications and conditions after the spinal cord lesion within the last year:**

- None
- Pneumonia: Number of episodes of pneumonia treated with antibiotics: \_\_\_\_\_ **NOEPANTB**
- PNEMONIA** \_\_\_\_\_ Number of episodes of pneumonia requiring hospitalization: \_\_\_\_\_ **NOEPHOSP**
- Asthma **ASTHMA**
- Chronic obstructive pulmonary disease (includes emphysema and chronic bronchitis) **COPD**
- Sleep apnea **SLEEPAPN**
- Other respiratory conditions, specify **OTHPULM** **OTHPULSP** \_\_\_\_\_
- Unknown

**Current Utilization of Ventilatory Assistance:**

- None **MECHVENT**
- Mechanical Ventilation:
  - Yes, less than 24 hours per day **MCVNTFRQ**
  - Yes, 24 hours per day
  - Yes, unknown number of hours per day
- Diaphragmatic pacing: Date inserted: YYYY/MM/DD **DPHRPCDT**
- Phrenic nerve stimulation: Date inserted: YYYY/MM/DD **PHNRSTD**
- Bi-level Positive Airway Pressure (BiPAP) Date started use: YYYY/MM/DD **BIPAPDT**
- PHNRVSTM** **DIPHRPAC** **BIPAP**
- Other, specify **OTVNTASS** **OVNTASSP** \_\_\_\_\_
- Unknown

**Table #2****Pulmonary function tests:**

Forced vital capacity (FVC): \_\_\_\_\_

Liters

FVCLTRS

Forced expiratory volume in one second (FEV1): \_\_\_\_\_

Liters

FEV1LTRS

Peak expiratory flow (PEF): \_\_\_\_\_

Liters/minute

PEFLTRMN

Pulmonary Function Basic

Proposed 8 Character Variables:

<b>Data Element</b>	Site	Subject	Date performed	Pulmonary conditions present before spinal cord lesion- Asthma	Pulmonary conditions present before spinal cord lesion- Chronic obstructive pulmonary disease (COPD)	Pulmonary conditions present before spinal cord lesion- Sleep apnea	Pulmonary conditions present before spinal cord lesion- Other	Pulmonary conditions present before spinal cord lesion- Other, Specify	Smoking history
<b>Format/ Codes</b>			Numeric (yyyymmdd) 9999-99-99 = Unknown	Yes; No (Default code); Unknown	Yes; No (Default code); Unknown	Yes; No (Default code); Unknown	Yes; No (Default code); Unknown	Free text	Never smoked; Former smoker; Current smoker; Unknown
<b>Table</b>	1 and 2	1 and 2	2	1	1	1	1	1	2
<b>8 Character Variable</b>	SITE	SUBJECT	PULMDT	ASTHMAHX	COPDHX	SLPAPNHX	OTHPULHX	OPULHXSP	SMOKNGHX
<b>Comments/ Notes</b>	key	key		If "None" selected for question on form then all conditions will be coded as No. If "Unknown" selected for question on form then all conditions will be coded as "Unknown".	If "None" selected for question on form then all conditions will be coded as No. If "Unknown" selected for question on form then all conditions will be coded as "Unknown".	If "None" selected for question on form then all conditions will be coded as No. If "Unknown" selected for question on form then all conditions will be coded as "Unknown".	If "None" selected for question on form then all conditions will be coded as No. If "Unknown" selected for question on form then all conditions will be coded as "Unknown".		

Pulmonary Function Basic

Proposed 8 Character Variables:

<b>Data Element</b>	Site	Subject	If a former smoker, which year did you quit smoking?	If a former or current smoker, for how many years did (have) you smoked?	If a former or current smoker, on average how many <b>cigarettes</b> do (did) you smoke on a daily basis?	If a former or current smoker, on average how many <b>cigars</b> do (did) you smoke on a daily basis?	If a former or current smoker, on average how many <b>pipe bowls</b> do (did) you smoke on a daily basis?	For former or current cigarette smokers only, the number of pack-years of smoking [(average number smoked daily)/20] x (number of years smoked)= __ pack-years
<b>Format/ Codes</b>			Numeric; 9999 = Unknown	Numeric; 999 = Unknown	Numeric; 999 = Unknown	Numeric; 999 = Unknown	Numeric; 999 = Unknown	Numeric; 9999 = Unknown
<b>Table</b>	1 and 2	1 and 2	2	2	2	2	2	2
<b>8 Character Variable</b>	SITE	SUBJECT	SMKQITYR	SMKNOYRS	NOCIGRTS	NOCIGARS	NOPIPES	SMKPCKYR
<b>Comments/ Notes</b>	key	key						

Pulmonary Function Basic

Proposed 8 Character Variables:

<b>Data Element</b>	Site	Subject	Pulmonary complications and conditions after the spinal cord lesion within the last year - Pneumonia	Pneumonia - number of episodes treated with antibiotics	Pneumonia - number of episodes requiring hospitalization	Pulmonary complications and conditions after the spinal cord lesion within the last year - Asthma	Pulmonary complications and conditions after the spinal cord lesion within the last year - COPD	Pulmonary complications and conditions after the spinal cord lesion within the last year - Sleep Apnea
<b>Format/ Codes</b>			Yes; No (Default code); Unknown	Numeric; 999 = Unknown	Numeric; 999 = Unknown	Yes; No (Default code); Unknown	Yes; No (Default code); Unknown	Yes; No (Default code); Unknown
<b>Table</b>	1 and 2	1 and 2	2	2	2	2	2	2
<b>8 Character Variable</b>	SITE	SUBJECT	PNEMONIA	NOEPANTB	NOEPHOSP	ASTHMA	COPD	SLEEPAPN
<b>Comments/ Notes</b>	<b>key</b>	<b>key</b>	If "None" selected for question on form then all conditions/ complications will be coded as No. If "Unknown" selected for question on form then all conditions/ complications will be coded as "Unknown".			If "None" selected for question on form then all conditions/ complications will be coded as No. If "Unknown" selected for question on form then all conditions/ complications will be coded as "Unknown".	If "None" selected for question on form then all conditions/ complications will be coded as No. If "Unknown" selected for question on form then all conditions/ complications will be coded as "Unknown".	If "None" selected for question on form then all conditions/ complications will be coded as No. If "Unknown" selected for question on form then all conditions/ complications will be coded as "Unknown".

Pulmonary Function Basic

Proposed 8 Character Variables:

<b>Data Element</b>	Site	Subject	Pulmonary complications and conditions after the spinal cord lesion within the last year - Other	Pulmonary complications and conditions after the spinal cord lesion within the last year - Other, Specify	Current Utilization of Ventilatory Assistance - Mechanical Ventilation	Mechanical Ventilation: Specify hours per day	Current Utilization of Ventilatory Assistance - Diaphragmatic pacing	Diaphragmatic pacing: Date inserted
<b>Format/ Codes</b>			Yes; No (Default code); Unknown	Free Text	Yes; No (Default code); Unknown	Less than 24 hours per day; 24 hours per day; Unknown number of hours per day	Yes; No (Default code); Unknown	Numeric (yyyymmdd) 9999-99-99 = Unknown
<b>Table</b>	1 and 2	1 and 2	2	2	2	2	2	2
<b>8 Character Variable</b>	SITE	SUBJECT	OTHPULM	OTHPULSP	MECHVENT	MCVNTFRQ	DIPHRPAC	DPHRPCDT
<b>Comments/ Notes</b>	key	key	If "None" selected for question on form then all conditions/ complications will be coded as No. If "Unknown" selected for question on form then all conditions/ complications will be coded as "Unknown".		If "None" selected for question on form then all types of assistance will be coded as No. If "Unknown" selected for question on form then all types of assistance will be coded as "Unknown".		If "None" selected for question on form then all types of assistance will be coded as No. If "Unknown" selected for question on form then all types of assistance will be coded as "Unknown".	

Pulmonary Function Basic

Proposed 8 Character Variables:

<b>Data Element</b>	Site	Subject	Current Utilization of Ventilatory Assistance - Phrenic nerve stimulation	Phrenic nerve stimulation: Date inserted	Current Utilization of Ventilatory Assistance - Bi-level Positive Airway Pressure (BiPAP)	BiPAP: Date inserted	Current Utilization of Ventilatory Assistance - Other	Current Utilization of Ventilatory Assistance - Other, specify
<b>Format/ Codes</b>			Yes; No (Default code); Unknown	Numeric (yyyymmdd) 9999-99-99 = Unknown	Yes; No (Default code); Unknown	Numeric (yyyymmdd) 9999-99-99 = Unknown	Yes; No (Default code); Unknown	Free Text
<b>Table</b>	1 and 2	1 and 2	2	2	2	2	2	2
<b>8 Character Variable</b>	SITE	SUBJECT	PHNRVSTM	PHNRSTDT	BIPAP	BIPAPDT	OTVNTASS	OVNTASSP
<b>Comments/ Notes</b>	key	key	If "None" selected for question on form then all types of assistance will be coded as No. If "Unknown" selected for question on form then all types of assistance will be coded as "Unknown".		If "None" selected for question on form then all types of assistance will be coded as No. If "Unknown" selected for question on form then all types of assistance will be coded as "Unknown".		If "None" selected for question on form then all types of assistance will be coded as No. If "Unknown" selected for question on form then all types of assistance will be coded as "Unknown".	

Pulmonary Function Basic

**Proposed 8 Character Variables:**

<b>Data Element</b>	Site	Subject	Pulmonary Function Tests - Forced vital capacity (FVC)	Pulmonary Function Tests - Forced expiratory volume in one second	Pulmonary Function Tests - Peak expiratory flow (PEF)
<b>Format/ Codes</b>			99.9 = Unknown; _._ (Liters)	99.9 = Unknown; _._ (Liters)	99.9 = Unknown; _._ (Liters)
<b>Table</b>	1 and 2	1 and 2	2	2	2
<b>8 Character Variable</b>	SITE	SUBJECT	FVCLTRS	FEV1LTRS	PEFLTRMN
<b>Comments/ Notes</b>	key	key			